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Original Article

Psychological state and needs of family member caregivers for victims of traumatic brain injury: A cross-sectional descriptive study

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ABSTRACT

Objective: Here we evaluated the impact of varying severity of traumatic brain injury on the psychological state and demands of family caregivers. Further, we determined the most significant and least significant daily needs among family caregivers.

Methods: We performed a cross-sectional descriptive study in three public hospitals in Tai'an, China. Three hundred caregivers related to traumatic brain injury victims were randomly selected. Patients had varying degrees of injuries (mild to severe). The Symptom Checklist-90 (SCL-90) was used to assess family caregivers' psychological statuses. The Critical Care Family Needs Inventory (CCFNI) was used to determine family caregivers' needs. Finally, the Glasgow Coma Scale (GCS) was employed to define patients' level of traumatic brain injury.

Results: SCL-90 scores for each psychological dimension were significantly higher with increasing TBI severity ($p < 0.05$). Similarly, CCFNI scores were significantly higher with increasing TBI severity ($p < 0.05$) for information, reassurance, and accessibility. These same dimensions were found to be the most important needs for family members of TBI injury victims, while support and comfort were the least important dimensions.

Conclusions: The more severe pathogenic condition of the patient, the heavier the psychological pressure is on their family member caregivers. Medical staff should therefore pay close attention to the psychological health of family caregivers of TBI patients, especially family caregivers of critical cases. Interventions should be accordingly designed and conducted to meet the needs of family caregivers.

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1. Introduction

Traumatic brain injury (TBI) is a common disease that causes death and disability around the world [1]. In the United States, TBI is the leading cause of disabilities in people under 40 years of age, disabling ~150–200 people per million each year [2]. In China, TBI accounts for ~60% of all injuries. The World Health Organization (WHO) predicts that TBI will be a leading cause of death by the year 2020 [3].

TBI results in cognitive, psychosocial, emotional, economic, and physical changes. These changes lead to a substantial impact on the lives TBI victims as well as their families [4]. TBI victims are often unable to live independent lives. Family members often take on the role of caregiver, resulting in disrupted social, vocational, recreational activities, and dramatic changes in daily routines [5]. As a result, caregiving is associated with psychological distress, anxiety and depression, financial problems, and decreased quality of life [6–8]. However, the daily needs of caregivers to ameliorate these burdens have not been thoroughly investigated. This is even more apparent in developing nations, where the burden of caregiving is greater due to additional barriers that increase their needs (e.g. lack of TBI rehabilitation, community resources, and social support networks).

Here we investigated the psychological states and daily needs of people providing care for a TBI family member. We determined the most significant and least significant needs among family caregivers, while also considering the degree of TBI injury. Such analyses may lead targeted approaches to help family caregivers maintain a healthy state of mind and meet their daily needs, while still sustaining caregiving.

2. Methods

2.1. Participants

Three hundred caregivers related to TBI victims were randomly selected. Patients had varying degrees of injuries (mild to severe). All participants were 18 years of age or older, were the main caregiver of a family member diagnosed with TBI, were able to understand and respond to research questions, and agreed to participate in the study. The Glasgow Coma Scale/Score (GCS) was used to define patients' degree of TBI. Patients with scores of 3–8 were considered severe, 9–12 were considered moderate, and scores of 13–15 were considered to be mild TBI. The Medical Ethical Committee at the Taishan Medical University Affiliated Hospital approved this study.

Our research team obtained consent from the College of Nursing and the management department of three nearby public hospitals. Family members who meet the inclusion criteria were invited to participate in the study and received information about its objectives. If they agreed, an interview appointment was scheduled. At the appointment, after learning about the study, caregivers were asked to sign informed consent forms in accordance with regulations approved by the Free and Informed Consent Terms. Interviews were held in a private location, and lasted 20–30 min.

2.2. Assessments

Three sets of data were collected from family caregivers, namely demographic characteristics of patients and their family caregiver, the Symptom Checklist-90 (SCL-90), and the Critical Care Family Needs Inventory (CCFNI). Each of these is described below.

2.2.1. Demographic characteristics of patients and their family caregiver

The family caregivers' gender, age, education level, occupation, economic income, and relationship to the patient were recorded. Patients' gender, age, duration of hospitalization, insurance, and severity of injury were also recorded.

2.2.2. Symptom Checklist-90 (SCL-90)

The Chinese version of the SCL-90 is a tool derived from Derogatis' SCL-90 from 1973. The scale assesses the psychological symptoms of subjects and has had high reliability and validity in Chinese studies [9]. Here we assessed the psychological states of family caregivers. The SCL-90 consists of 90 questions, each of which is answered on a 5-point scale of degree of distress. It includes nine primary symptom dimensions, namely somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism. The SCL-90 has been proven to be particularly useful in discriminating symptoms related to depression and anxiety [10]. We investigated whether there was a relationship between the three traumatic brain groups (mild, moderate, severe) and the results of the SCL-90.

2.2.3. Critical Care Family Needs Inventory (CCFNI)

We assessed the needs of family caregivers of TBI victims using the Critical Care Family Needs Inventory (CCFNI), which was revised by Leske in 1991 [11]. The CCFNI consists of 45 needs items, and scoring is based on their importance. The items were classified into five dimensions: support, comfort, information, accessibility, and reassurance [12,13]. The CCFNI has been adapted and validated for Chinese culture. It was translated into Chinese and its Cranach's alpha coefficient is 0.89 [14]. The scoring scale ranges from 1 to 4, and was also adopted in the present study. The higher the score attributed to the item, the higher the level of need.

2.3. Data analysis

All statistics were performed in SPSS 13.0 for Windows. Basic characteristics of patients and their respective relatives were described by descriptive statistics. All comparisons were performed with variance analysis and Kruskal–Wallish tests. Statistical significance was defined as $p < 0.05$.

3. Results

3.1. Demographic characteristics of patients and their family caregiver

66% of TBI patients were male, while 34% patients were female. 13.7% of patients had mild TBI, 36.3% patients had

moderate TBI, and 50% of patients had severe TBI. Of the family caregivers, 48% were spouses. 42% were farmers and their income was low. For a complete list of demographic characteristics, see Table 1.

3.2. *Symptom Checklist-90 (SCL-90)*

We compared SCL-90 scores of the nine primary symptom dimensions with moderate, mild, and severe TBI (Table 2). The scores of all nine symptom dimensions in the severe TBI group were significantly higher than those in the mild TBI group. Similarly, all moderate TBI scores were significantly higher than the mild TBI group.

Table 1 – Characteristics of patients and family members ($n = 300$).

Parameters	Composition
Patient gender	
Male	66.0%
Female	34.0%
Patient age groups (years)	
0–15	5.0%
16–29	23.3%
30–39	42.7%
40–49	16.3%
>50	12.7%
Length of hospitalization (days)	
0–7	28.3%
8–30	50.7%
31–90	13.3%
91–180	4.0%
181–365	2.3%
>366	1.4%
Insurance	
Medicaid/self-pay	68.0%
Commercial	32.0%
Severity of injury	
Mild	13.7%
Moderate	36.3%
Severe	50.00%
Family caregiver gender	
Male	39.7%
Female	60.3%
Family age groups (years)	
18–29	24.0%
30–39	30.0%
40–49	29.7%
>50	16.3%
Family caregiver education level	
Primary	43.4%
Secondary	30.0%
College/University	26.6%
Relationship to the patient	
Spouse	48.0%
Parent	20.0%
Child	16.0%
Sibling	13.3%
Other family member	2.7%
Family level of income	
Low-level income/dependent	39.0%
Middle-level income	46.0%
High-level Income	15.0%
Family employment status	
Farmers	42.0%
Official/teacher	25.0%
Self-employed persons	17.0%
Housewives/retired	16.0%

3.3. *Critical Care Family Needs Inventory (CCFNI)*

Lastly, we compared needs of family caregivers of mild, moderate, and severe TBI victims using the CCFNI (Table 3). We found significant associations between the level of TBI severity and information needs, closeness needs, and reassurance needs ($p < 0.05$). The needs for information, accessibility, and reassurance in the severe TBI group were significantly higher than the mild and moderate TBI group. We also examined which family needs were most important and least important. As shown in Table 4, we found that needs related to reassurance, closeness, and information were the most important to TBI family caregivers. In contrast, needs associated with accessibility, support, and reassurance and comfort were the least important to TBI family caregivers (Table 5).

4. Discussion

Many family caregivers play key roles in their relative's TBI rehabilitation process. As a result, caregivers have increased risks for anxiety disorders, mood disorders, and social adjustment difficulty [15]. The data presented here are in line with these earlier findings. We expand upon the findings by showing that as the severity of TBI increases, the more burdensome it is on family caregivers.

Previous studies show that immediately after TBI, families often show a variety of grief reactions as they come to terms with the reality of the injury. Many families first experience denial of the injury's consequences for the affected family member. Later, grief can include depression, anger, and anxiety [5]. Muir and Haffey suggested that TBI family grief reactions are similar to the death grieving model described by Kubler-Ross. Further, they write that TBI victims' families grieve in a "mobile mourning" fashion, as they cope with the fact that the person with TBI may never fully regain pre-injury functional capacities. These observations suggest that the psychological state of family caregivers is closely related to the patients' condition. Caregivers must often coordinate the patients' rehabilitation, provide care, and made important decisions. Family caregivers must often in addition deal with medical expenses (in China, most individuals must pay the majority of medical expenses) and potentially with disputes. These burdens increase their risk for various psychological disorders.

We found that high psychological pressure of family caregivers led to poor interpersonal relationships, physician–patient relationships, and nurse–patient relationships. These conflicts interfered with treatment, which had adverse impacts on patient recovery. In several cases, family members disagreed on approach to caregiving or disputed over medical expense issues. Some family caregivers did not understand the patients' severity clearly, and therefore may not have made proper decisions in method of treatment. It is therefore

Table 2 – Scores of nine SCL-90 symptom dimensions in mild, moderate, and severe TBI groups.

	Mild TBI	Moderate TBI	Severe TBI	F value	*p* value
Somatization	1.21 ± 0.62	1.77 ± 0.51	2.65 ± 0.53	15.374	<0.001
Obsessive-compulsive	1.41 ± 0.55	1.76 ± 0.46	2.51 ± 0.53	10.726	0.001
Interpersonal sensitivity	1.43 ± 0.52	1.82 ± 0.48	2.49 ± 0.56	9.529	0.001
Depression	1.47 ± 0.46	1.91 ± 0.51	2.36 ± 0.39	8.572	0.002
Anxiety	1.48 ± 0.44	1.92 ± 0.52	2.15 ± 0.46	4.632	0.020
Hostility	1.49 ± 0.38	1.81 ± 0.52	2.08 ± 0.52	3.928	0.034
Phobic anxiety	1.52 ± 0.45	1.96 ± 0.53	2.46 ± 0.56	7.494	0.003
Paranoid ideation	1.68 ± 0.39	1.97 ± 0.45	2.35 ± 0.36	6.296	0.006
Psychoticism	1.44 ± 0.56	1.81 ± 0.49	2.44 ± 0.51	8.481	0.002

Table 3 – Scores of five CCFNI needs dimensions in mild, moderate, and severe TBI groups.

	Support	Comfort	Information	Accessibility	Reassurance
Mild TBI	2.14 ± 0.52	2.54 ± 0.62	2.70 ± 0.43	2.29 ± 0.37	3.08 ± 0.52
Moderate TBI	2.36 ± 0.51	2.05 ± 0.67	2.93 ± 0.42	2.71 ± 0.35	3.31 ± 0.55
Severe TBI	2.49 ± 0.46	2.36 ± 0.61	3.62 ± 0.46	2.90 ± 0.31	4.21 ± 0.47
F value	0.633	0.765	6.002	4.111	6.739
p value	>0.05	>0.05	<0.05	<0.05	<0.05

Table 4 – Needs rated as most important by family caregivers.

Order	Item number	Needs	Dimension
1	14	To feel there is hope	Reassurance
2	1	To know the expected outcome	Reassurance
3	17	To be assured that the best care possible is being given to the patient	Reassurance
4	39	To receive information about the patient at least once a day	Closeness
5	43	To have the waiting room near the patient	Closeness
6	5	To have questions answered honestly	Reassurance
7	41	To know specific facts concerning the patient's progress	Reassurance
8	13	To know why things were done for the patient	Information
9	42	To see the patient frequently	Closeness
10	16	To know how the patient is being treated medically	Information

important to understand the psychological state and characteristics that influence the family caregivers' psychological problems. A better understanding may lead to more targeted approaches to help family caregivers maintain a healthy state of mind, to meet their daily needs, and improve the outcome for those with TBI.

We also report here that information needs, accessibility needs, and reassurance needs were significantly higher in the severe TBI group than in the mild and moderate TBI groups.

Since the risk of mortality or disability in patients with severe TBI is larger than moderate or mild TBI, one would expect that these family caregivers are more worried about the patients' safety and prognosis than those with mild or moderate TBI. Appropriately, we find that family caregivers of severe TBI victims have more serious psychological problems and they need more accessibility from others. Similarly, these patients also need prolonged hospitalization, longer-term care. Thus, economic and psychological stress of

Table 5 – Needs rated as least important by family caregivers.

Order	Item number	Needs	Dimension
1	37	To be told about transfer plans while they are being made	Closeness
2	03	To feel it is all right to cry	Support
3	33	To have explanations given that are understandable	Reassurance
4	24	To have a pastor visit	Support
5	23	To have a telephone near the waiting room	Comfort
6	32	To have a toilet near the waiting room	Comfort
7	45	To have the waiting room near the patient	Closeness
8	36	To help with the patient's physical care	Information
9	28	To be assured it is alright to leave the hospital for a while	Comfort
10	31	To be told about other people that could help with problems	Support

family with severe TBI is greater than mild or moderate TBI. However, it should be noted that significant variability in the physical, cognitive, and social aspects of TBI recovery exists, making the prognosis for the individual uncertain [16]. As a result, families often exhibit intensive needs for information and emotional support as they struggle to adapt to the changes in their life style [17].

We found that the most important needs for family caregivers were reassurance, accessibility, and information. More specifically, they needed to feel there was hope [18], to know the expected outcome [19], to be assured that the best care possible was being given to the patient [20], and they needed to receive the latest information about the patient at least once a day. The need for hope has been identified in several studies. While families want to receive realistic information regarding the patient's prognosis, they also want medical professionals to give them hope for the future. In contrast, the least important dimensions for family caregivers were support and comfort. More specifically, they did not feel the need to be told about changes in treatment plans and did not need to feel that it was all right to cry.

Families relied on professional staff to encourage them to maintain hope and paid close attention to words of encouragement. Nurses were identified as providing support most often (~50% of the time). Nurses are responsible for providing or coordinating interventions, sharing information, coordinating family conferences, regulating visiting hours, and bedside family/patient interactions to meet the family's need for support, comfort, information, accessibility, and assurance. Nurses may be so valued due to so many intimate hours with both the patients and families, thereby developing close relationships. Competence and effective communication were two key descriptors for nursing care. These qualities should therefore be emphasized to nurses so that they provide holistic care to TBI patients.

5. Conclusion

The present study found that the more severe a TBI patient is, the heavier the psychological pressure is on their family member caregiver. The relatives of patients required information, accessibility, and reassurance to deal with their psychological burden. These findings suggest that medical staff should pay more attention to the psychological health of caregivers and enhance communication with family caregivers. Our study underscores the importance of meeting the needs of family member caregivers. Future studies should focus on how to reduce psychosocial disorders, build family confidence in the health care system, and ultimately improves patients' outcomes.

Conflict of interest

The authors declare that there are no conflicts of interest.

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